IN THIS TOGETHER
parkinson's
NSW

In Touch Newsletter
March 2025

What did the Support Group Communications Survey tell us?

The very first Support Group Communications Survey took place in the final quarter of 2024. Fifty-nine in-person Groups were invited to participate and 21 Groups responded by completing the questionnaire.

In all, 321 individuals responded. Based on their input we were able to obtain the following feedback:

Preferred Method of Communications

1. Emails with files attached
2. Printed publications
3. Emails without files attached
4. Emails printed out by the Group and distributed to participants as hard copies
5. Information passed on verbally by Support Group Leaders
6. Texts
7. Web site visits
8. Participation in Zoom meetings
9. Information summarized in Group newsletters
10. Phone calls

Preferred Frequency of Communications

65%
Monthly
18%
Weekly
14%
Quarterly
3%
Never

Desired Topics for Communications

1. Articles on Parkinson's NSW services and supports
2. Research updates
3. Articles on exercise, health, and wellbeing
4. News about Support Group activities
5. Latest health updates from the InfoLine team
6. Articles for care partners
7. Articles on how others are living with Parkinson's
8. News about general Parkinson's NSW activities
9. Updates on Parkinson's NSW advocacy
10. Updates on Parkinson's NSW fundraising activities

Suggested Future Subjects for Coverage

- More on opportunities to participate in clinical trials
- Updates on progress being made in research
- Recommendations on good books to read about Parkinson's
- Highlight Support Group Committees which are doing a good job and how they are doing this
- More information about DBS and Parkinson's Plus conditions
- Add more YouTube videos as sources of Parkinson's NSW information
- Publish evaluations of Parkinson's health and mobility aids
- More updates on advances in treatments and medication breakthroughs
- Article on how Parkinson's affects your driving

"We are already taking action on these suggestions," said Stacey Foster, Support Group Coordinator of Parkinson's NSW. "Articles on suggested topics are underway for our monthly *InTouch* newsletter, and we have committed to producing more videos in future – starting from coverage of our upcoming Support Group Leadership Conference.

"It was also interesting for us to learn from the survey that 60 percent of respondents were completely unaware of the fact that Parkinson's NSW services and supports are paid for from fundraising. We receive just 10 percent of our funding from Government grants," she said. "There was a widespread assumption that everything is paid for by Government, and unfortunately that is not correct."

Do you have any questions about this survey? Contact Communications Manager John Back at john.back@parkinsonsnsw.org.au

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Understanding Parkinson's Disease Dementia

Many Parkinson's patients have no cognitive impairment while others develop mild cognitive impairment which does not affect their ability to perform daily tasks independently.

However, an estimated one-quarter of patients diagnosed with Parkinson's develop Parkinson's disease dementia (PDD), according to Jumana Alshaikh MD, Assistant Professor in the Department of Neurology and Co-director of the Parkinson's Disease Center of Excellence at the University of Utah.

"For some patients, their cognitive impairment progresses to a point where they have dementia," Alshaikh explained, "meaning that their cognitive symptoms affect their ability to be independent and they need help from others for their day-to-day tasks."

According to an article in the *Journal of Neurological Sciences*, dementia is more likely for patients who have been living with Parkinson's for more than 10 years. Additionally, Alshaikh said that patients who are diagnosed with Parkinson's at an older age are more at risk for PDD.

"Also, the more advanced and severe your other Parkinson's symptoms are, the more at risk you are to develop PDD," she said.

PDD Symptoms

Patients who develop PDD experience impairments in different areas of cognition. More prominently, these impairments occur in executive and visuospatial functions and attention, which include difficulties planning, organising, dressing, driving, and multitasking.

Although PDD patients may experience forgetfulness – a hallmark of Alzheimer's disease – it is often due to disorganisation of thoughts, Alshaikh said, and patients might be able to recall things when provided clues. Patients with PDD can also develop other symptoms such as hallucinations and delusions.

How is PDD Diagnosed?

PDD is diagnosed after the patient has an established diagnosis of Parkinson's disease and develops cognitive symptoms that start after at least one year from the time that movement symptoms of Parkinson's began. For the cognitive impairment to be called dementia, it must be severe enough that the patient requires assistance from others to complete their daily activities.

“We base this information from the history provided by the patient and their caregivers,” Alshaikh said, “and then we perform cognitive assessments with an office-based cognitive test such as the MoCA (Montreal Cognitive Assessment). If further information is needed, we may perform additional testing, refer the patient to a neuropsychologist for more detailed cognitive assessments, or order imaging studies such as an MRI brain or PET scan to rule out other causes of dementia.”

Treatment for PDD

Medications can help treat PDD. These medications boost levels of acetylcholine, a chemical in the brain that is involved in cognition and memory. Increasing the levels of acetylcholine can even help with hallucinations related to Parkinson's.

Some patients with severe hallucinations may also need anti-psychotic medications, though Alshaikh recommends caution about which of those medications can be prescribed. Some of those medications need to be avoided since they can worsen the movement symptoms associated with Parkinson's.

Medications only alleviate the symptoms of PDD. However, they don't reverse the underlying disease process or slow down what's happening in the brain.
But some studies suggest exercising regularly – "…especially exercises that get your heart rate up," Alshaikh said. "Aerobic exercises or cardio exercises might have an effect on slowing down the progression of Parkinson's disease. In addition to that, exercise can also improve cognition and memory."

Physical activity must be tailored to the patient's abilities and movement issues associated with Parkinson's disease, which is why it's ideal to set up an exercise program with a physical therapist.
Additionally, it's important to look at other things that might contribute to the patient's cognitive symptoms.

"For example, poor sleep quality can make cognition worse since sleep plays an important role in the consolidation of our memories," Alshaikh said. Problems like anxiety or depression and hearing impairment can also worsen cognition.

Tips for Caregivers

Alshaikh has these suggestions for caregivers:

- Encourage your loved one with PDD to exercise regularly and engage in activities that they enjoy.
- Be present for medical appointments so that you can provide important collateral information to their doctors that can help with their treatment.
- Get involved with helping your loved one implement the treatment plan discussed with their doctor.
- Try to create an environment or opportunities for social interaction.
- Be patient as a Parkinson's patient may be slower to respond to questions. Don't assume that because they take a long time to answer, they don't know the answer to a question.
- Regularly review the patient's medications with their neurologist to see whether medications are making cognition worse – these could be medications given for other routine medical conditions.

If cognition declines rapidly or suddenly and your loved one or patient becomes much more confused than normal, seek medical attention right away as a medical problem such as a urinary tract infection could be exacerbating the PDD symptoms.
Caregivers are often unprepared for many of the tasks and challenges they will face. Educating yourself and practicing self-care are important tools for success.

You can obtain valuable information and advice on the matters raised in this article by calling the Parkinson's NSW InfoLine on 1800 644 189.
Sources:
Journal of Neurological Sciences
University of Utah

How to overcome barriers to physical activity

"*You cannot get someone to engage in a serious wellness plan, including exercise, until they feel that there is hope. They have to trust that there's something meaningful to look forward to and live for. For people who are newly diagnosed and for anyone who is having trouble motivating themselves to exercise, I would reiterate that this is not the beginning of the end, but the beginning of a new journey that can be rewarding and happy, as long as you allow it to be.*"
– Steve Hovey, Davis Phinney Foundation Ambassador living well with Parkinson's

Exercise is a wonderful way to improve both physical symptoms and overall quality of life for people living with Parkinson's. However, starting or sticking with an exercise routine can feel challenging for many.
Research shows that there are three main reasons people with Parkinson's may hesitate to exercise:

1. Expecting little to no return for the effort
2. Doubting their ability to achieve benefits.
3. Fear of falling

These are understandable concerns, but it's important to remember that, like Parkinson's symptoms, each person's barriers to exercise can be unique. Whether it's related to health issues, personal circumstances, or external factors, we all face different challenges.

Health-related barriers for people with Parkinson's can include stiffness, balance issues, anxiety, fatigue, and pain.

On a personal level, things like taking care of family members, work responsibilities, or not having enough time can make it tough to prioritise exercise.

External factors like living in a remote area, lack of public transportation, or bad weather can also get in the way.

But don't worry! There are plenty of ways to overcome these obstacles and get moving. Here are a few suggestions:

- **Seek Professional Guidance:** If you're struggling to exercise due to a specific symptom, it's a good idea to talk to your doctor. They might adjust your Parkinson's medication to help. You can also consult a Parkinson's exercise specialist who can help you learn how to work around your barriers.
- **Social Support:** Join an exercise class designed for people with Parkinson's, where the activities are safe and effective. Exercising with others can be motivating, and it adds a sense of accountability.
- **Exercise When You Feel Your Best:** Try to schedule your workouts when your medication is working well and you're feeling at your peak. If your meds aren't working as usual, feel free to adjust your routine.
- **Reward Yourself:** Celebrate small victories! Setting exercise goals and rewarding yourself when you meet them can be a great motivator.
- **Mix Up Your Routine:** Keep things fun by trying different types of exercise. Variety not only keeps you engaged but also helps you step outside your comfort zone and try new things.
- **Adjust for Fatigue:** On days when you feel more tired, choose lower-intensity activities like yoga or walking. When you're feeling energized, go for something more intense, like swimming or dancing. Always make sure to rest and recover when needed.

Overcoming Personal Barriers

- **Low Confidence/Fear of Falling:** Keep track of your achievements, no matter how small, to build motivation. An exercise buddy can help make things feel less intimidating, too!
- **Physical Discomfort:** Listening to music during your workouts can help distract from any discomfort. And be ready to adjust your routine depending on how you feel physically and mentally each day.
- **No Previous Exercise Experience:** Try to make exercise part of your daily routine. If you're new to it, start small and focus on consistency. You can break up your exercise into short sessions throughout the day and remember that even a little bit of exercise adds up!
- **Lack of Time:** If time is a barrier, consider integrating exercise into everyday tasks, like gardening or walking the dog. You can also try virtual exercise classes, which eliminate the need for transportation and can be done in the comfort of your own home.

Exercise doesn't need to be overwhelming. Find what works for you and take it one step at a time. The important thing is to keep moving and enjoy the benefits that come with it!

References:
https://www.simplypsychology.org/self-efficacy.html
https://pmc.ncbi.nlm.nih.gov/articles/PMC3641403/
https://davisphinneyfoundation.org/how-to-encourage-people-with-parkinsons-to-exercise/

Taming Parkinson's Disease with Intelligent Brain Pacemakers

Two new studies from University of California (UC) San Francisco are pointing the way toward round-the-clock personalised care for people living with Parkinson's disease through an implanted device that can treat movement problems during the day and insomnia at night.

The approach – called adaptive Deep Brain Stimulation, or aDBS – uses methods derived from Artificial Intelligence (AI) to monitor a patient's brain activity for changes in symptoms.

When it spots them, it intervenes with precisely calibrated pulses of electricity. The therapy complements the medications that Parkinson's patients take to manage their symptoms, giving less stimulation when the drug is active (to ward off excess movements) and more stimulation as the drug wears off (to prevent stiffness).

It is the first time a so-called 'closed loop' brain implant technology has been shown to work in Parkinson's patients as they go about their daily lives. The device picks up brain signals to create a continuous feedback mechanism that can curtail symptoms as they arise. Users can switch out of the adaptive mode or turn the treatment off entirely with a hand-held device.

For the first study, researchers conducted a clinical trial with four people to test how well the approach worked during the day, comparing it to an earlier brain implant DBS technology known as constant or cDBS.

To ensure the treatment provided the maximum relief to each participant, the researchers asked them to identify their most bothersome symptom. The new technology reduced them by 50%.

The Future of Deep Brain Stimulation

"This is the future of Deep Brain Stimulation for Parkinson's disease," said Philip Starr, MD, PhD, the Dolores Cakebread Professor of Neurological Surgery and Co-Director of the UC San Francisco Movement Disorders and Neuromodulation Clinic and one of the senior authors of the study.

Starr has been laying the groundwork for this technology for more than a decade. In 2013, he developed a way to detect and then record the abnormal brain rhythms associated with Parkinson's. In 2021, his team identified specific patterns in those brain rhythms that correspond to motor symptoms.

“There’s been a great deal of interest in improving DBS therapy by making it adaptive and self-regulating, but it’s only been recently that the right tools and methods have been available to allow people to use this long-term in their homes,” said Starr.

Earlier this year, UC San Francisco researchers led by Simon Little, MBBS, PhD, demonstrated that adaptive DBS has the potential to alleviate the insomnia that plagues many patients with Parkinson’s.

“The big shift we’ve made with adaptive DBS is that we’re able to detect, in real time, where a patient is on the symptom spectrum and match it with the exact amount of stimulation they need,” said Little, Associate Professor of Neurology and a senior author of both studies.

Restoring movement

Parkinson’s disease affects about 10 million people around the world. It arises from the loss of dopamine-producing neurons in deep regions of the brain that are responsible for controlling movement. The lack of those cells can also cause non-motor symptoms, affecting mood, motivation, and sleep.

Treatment usually begins with levodopa, a drug that replaces the dopamine these cells are no longer able to make. However, excess dopamine in the brain as the drug takes effect can cause uncontrolled movements, called dyskinesia. As the medication wears off, tremor and stiffness set in again.

Some patients then opt to have a standard cDBS device implanted, which provides a constant level of electrical stimulation. Constant DBS may reduce the amount of medication needed and partially reduce swings in symptoms. But the device also can over- or under-compensate, causing symptoms to veer from one extreme to the other during the day.

Closing the loop

To develop a DBS system that could adapt to a person's changing dopamine levels, Starr and Little needed to make the DBS capable of recognising the brain signals that accompany different symptoms.

Previous research had identified patterns of brain activity related to those symptoms in the subthalamic nucleus, or STN, the deep brain region that coordinates movement. This is the same area that cDBS stimulates, and Starr suspected that stimulation would mute the signals they needed to pick up.

So, he found alternative signals in a different region of the brain, called the motor cortex, that wouldn't be weakened by the DBS stimulation.

The next challenge was to work out how to develop a system that could use these dynamic signals to control DBS in an environment outside the lab.

Building on findings from adaptive DBS studies that he had run at Oxford University a decade earlier, Little worked with Starr and the team to develop an approach for detecting these highly variable signals across different medication and stimulation levels.

A better night's sleep

Continuous DBS is aimed at mitigating daytime movement symptoms and doesn't usually alleviate insomnia.

But in the last decade, there has been a growing recognition of the impact that insomnia, mood disorders and memory problems have on Parkinson's patients. To help fill that gap, Little conducted a separate trial that included four patients with Parkinson's and one patient with dystonia, a related movement disorder.

In their paper published in *Nature Communications*, first author Fahim Anjum, PhD, a postdoctoral scholar in the Department of Neurology at UC San Francisco, demonstrated that the device could recognise brain activity associated with various states of sleep. He also showed it could recognise other patterns that indicate a person is likely to wake up in the middle of the night.

Little and Starr's research teams have started testing new algorithms to help people sleep. Scientists are now developing similar closed-loop DBS treatments for a range of neurological disorders.

"We see that it has a profound impact on patients, with potential not just in Parkinson's but probably for psychiatric conditions like depression and obsessive-compulsive disorder as well," Starr said. "We're at the beginning of a new era of neurostimulation therapies."

Sources
Original article by Robin Marks
University of California San Francisco

Choosing the right shoes for Parkinson's

Wearing comfortable footwear is important for helping you move around properly and help ease Parkinson's symptoms you experience in your feet or legs.

Here are some tips for choosing the right footwear for you.

1. **Get the right fit**

A good fitting shoe should have:

- around 1cm of space between the end of your longest toe and the top of the shoe
- enough depth and width so that you can move your toes easily, without touching the lining

Shoes that don't fit correctly can damage your feet and increase your risk of tripping over or falling. Wearing shoes that are too narrow can lead to your toes becoming cramped and may overlap. This can prevent your foot from staying balanced and moving around effectively.

Remember that if a shoe needs 'breaking in', it might not fit you or be comfortable day to day.

2. **Look for the right fastening**

A well-fitting shoe should not move at your heel when you move, so choose a good fastening that stops your foot from sliding forward.

Shoes with laces, Velcro fastenings or a strap and buckle will have a better hold on your foot than a slip-on shoe.

Try to avoid wearing slippers, as these don't give the same support as shoes.

3. **Pick the right height**

If you wear heels that are too high, too much pressure is put on the balls of your feet and knee joints. This can cause pain and affect movement.

Try to choose shoes that have a low, wide heel, and that fasten over the top of your foot, close to the ankle.

4. **Choose the right material**

Trainers made from natural or breathable fibres can often provide a good fit and strong support.

Avoid wearing leather-soled shoes, as they could increase the risk of trips and falls.

5. **Shop at the right time**

If you experience oedema (a buildup of fluid in your feet, ankles, and lower legs) or other foot problems such as dystonia, try to shop for shoes when your symptoms are at their worst. This will help you find shoes that always fit well.

If you're not able to go out shopping, you could order shoes online and return any that aren't suitable.

If a podiatrist has prescribed inserts or arch supports to wear in your shoes, make sure you have these with you when trying on new shoes.

Source:
Parkinson's UK

Walking to a new beat with *Walking Tall*

A simple yet powerful digital phone application called *Walking Tall* is helping people around the world improve their gait and better support their general health. Launched in 2023, the concept of *Walking Tall* has now been further developed.

University of NSW biomedical engineer Associate Professor Matthew Brodie developed the application which is helping tens of thousands of individuals combat difficulties in walking. With the help of research fellow and Director of Parkinson's NSW, Martin Ostrowski, the two have focused their efforts on assisting those suffering from health concerns that impact their ability to walk.

These include but are not limited to Parkinson's disease, diabetes, stroke, heart failure, kidney disease, dementia and sleep issues. The *Walking Tall* application has been translated into multiple languages and made freely available for worldwide community use via the Apple App Store and Google Play.

“We wanted to create technology that could help people walk because insufficient physical exercise is a major risk factor for a number of conditions,” said Associate Professor Brodie. “This is what's inspired me to create research that one day could potentially help over 100 million people walk with confidence.”

The *Walking Tall* application works by delivering a simple metronomic beat across three different walking speeds that have been designed to trigger movement. With everyday use of the application, individuals can not only learn to walk better but walk for longer, reduce falls, and improve overall mobility.

A personal connection

With his own history of Parkinson's disease, Dr. Ostrowski has used his lived experience to help with the application's development.

“When I first came into contact with Matthew, I was running 35km a week but over time that degraded into less than 2km per week,” he explained.

Following his participation in the application's first trial, Dr. Ostrowski was able to return to running 35km a week within two months. What truly surprised him, however, was how his other health concerns also improved.

"I'd had trouble with breathing but simply going out and walking gave me a chance to stand up straight and fill up my lungs," he adds. "I had to learn how to walk and run again, but without the app I'm not quite sure where I'd be."

The next step

The application, which was released in 2023, has already proven hugely popular with users, as well as industry peers and collaborators.

"The work done by Matt Brodie and Walking Tall Health targets an incredibly serious global problem, namely difficulties with motor function and walking," explained Professor Arun Krishnan – a neurologist at Prince of Wales Hospital and member of the faculty of Medicine and Health at UNSW.

"In most neurodegenerative conditions, there are no established methods of helping people to remain independent and ambulant, and while the early studies of the app have been undertaken in Parkinson's Disease, there are a large number of conditions including diabetes and stroke in which this technology fills an important gap in treatment," he said.

Thanks to the application's ongoing success, Associate Professor Brodie is now committed to the next phase of the project. This includes a wearable band solution that can be strapped to the users' arms or ankles.

In this instance, a prototype is to be attached to bands and worn above the ankles. The new device will work by synchronising neuronal stimulation across limbs, which has already been proven to help people with spinal cord injury regain function.

"As a neurologist who sees these patients on a daily basis, I feel very optimistic about how this technology could improve health outcomes for patients with many neurological disorders," added Professor Krishnan.

People who have diseases such as Parkinson's have to concentrate on every single step when they walk. The bands help the wearer put one foot in front of the other without the need to focus so intensely on the act of walking.

"I remember the first time I used the bands," recalls Dr. Ostrowski. "I put them on, and I knew almost immediately that it was working, because instead of thinking about walking I was thinking about what I was going to cook for dinner that night."

This new technology takes away the need to think about walking by providing stimulation matched to the intention of walking.

"I've noticed people using this device who previously couldn't walk and talk, turn around and joke to me while I'm asking them to concentrate on putting one foot in front of the other," added Associate Professor Brodie.

"I've noticed people using this device who previously couldn't walk and talk, turn around and joke to me while I'm asking them to concentrate on putting one foot in front of the other," he added.

While the Walking Tall application provides the metronome beat and can measure how you're walking, the bands work in combination with the app.

"If you want the legs to move, you put the device on the legs. If you want the arm to move, you put it on your arms. The more you put on, the more effective it is," explained Associate Professor Brodie.

Sensing progress and progression

While the software and technology being developed by Associate Professor Brodie and Dr. Ostrowski is helping those with chronic conditions overcome their walking challenges, it's also perfect for individuals recovering from knee or hip replacements. The connected sensors can also help to track disease progression. "They're sending feedback to the neurologist and physiotherapist, which allows them to customise intervention in real time and remotely look for red flags," explained Associate Professor Brodie.

Importantly, preliminary analysis of participants using the new devices and phone app suggest there might be an added benefit of less falls by users.

"We've seen a staggering 300% reduction in falls and related injuries and noticed that people are exercising 2.5 times longer than usual," he said.

"They're now breaking 150-minutes per week of exercise, which aligns with the World Health Organisation (WHO) recommended minimum to prevent falls and chronic co-morbidities."

The far-reaching impact of the application has been hugely rewarding for both men. "I've been a scientist for more than 25 years but being able to work on something that has direct impact is really attractive," said Dr. Ostrowski. "The moment you start walking well, everything gets better."

Source:
University of NSW

Take 5 - February 2025

A monthly review of the top five issues raised in calls to the Parkinson's NSW InfoLine team (call 1800 644 189).

1. **Constipation:**
   Constipation is a common challenge for people living with Parkinson's, often linked to the condition itself or certain medications. Strategies to manage this include dietary adjustments, hydration, and gentle exercise. For more guidance, our team can provide resources or connect you with a dietitian experienced in Parkinson's care.
2. **Voluntary Assisted Dying (VAD) in NSW:**
   With the introduction of Voluntary Assisted Dying laws in NSW, individuals and carers may have questions about eligibility and the process. Our InfoLine team

can provide general guidance, discuss the role of your healthcare providers, and offer resources to help you navigate this sensitive topic.

3. **Accessing My Aged Care:**
   It's important to arrange a My Aged Care assessment early, ideally before support is urgently needed. This proactive approach ensures you or your loved one are ready to access the services and support you need when the time comes. To get started, contact My Aged Care at **myagedcare.gov.au** or call **1800 200 422** for guidance on the assessment process and available services.
4. **Accessing the NDIS:**
   The NDIS provides support for people under 65 who have a permanent and significant disability that impacts their ability to carry out daily activities. For those eligible, Parkinson's NSW offers assistance through our NDIS Advocate, who can help with applications, pre-planning for NDIS meetings, and ongoing advocacy to ensure the services align with your needs. If you're unsure about your eligibility, contact us or the NDIS directly for more information.
5. **Dexterity Problems and Adaptive Clothing:**
   Dexterity challenges are common in Parkinson's and can make tasks like dressing more difficult. Adaptive clothing is designed to simplify dressing, featuring options like magnetic fastenings, easy-open designs, and elasticated materials. These innovations can support independence and reduce frustration in daily life. Our team can guide you on where to find adaptive clothing solutions in Australia.

Support Group Round-up

By Stacey Foster, Support Group Coordinator

Welcome to the March/April Support Group round-up. Before I talk about the Support Group Leaders Conference and Community Symposium, I would like to acknowledge some changes in leadership.

Northern Rivers (Ballina): We farewelled and said thank you to Cheryl Beerens after almost 6 years. We welcome Ian Dall, the group's new leader.

Dubbo: We farewelled and said thank you to Jim and Barbara Jupp after 6 years. Welcome to Marsha Isbester, their new leader.

Eurobodalla: We will farewell and say thank you to Joy Overs, Secretary of the group for 10 years. Joy also travelled to Canberra last year, representing the wider Support Group community, at a Parliament House meeting and reception to mark the formation of the National Parkinson's Alliance.

Tumut: We will farewell and say thank you to Barry Whiting after 3 years. Barry established the group and was passionate about raising awareness in the community as well as funds for Parkinson's NSW. Tumut Support Group will continue with participants pitching in to keep it going.

Parkinson's Awareness Month

If you or your support group are involved in an activity or event for Awareness Month, please share it with me so I can put it in the next *InTouch.* Photos and a short summary of what you did, people you spoke to, interesting stories etc would be great to share!

Support Group Leaders Conference & Community Symposium

Across two days in early April, Support Group Leaders travelled to the Sydney Masonic Centre for the first Leaders Conference since 2019 and our Community Symposium. It was a fantastic way to kick off Parkinson's Awareness Month!

There were almost 70 leaders and committee members in attendance, most of them having travelled from regional and rural areas.

It was important for us that the group were collectively recognised and appreciated as volunteers, so the first speaker of the day was Diana Piper from the Centre for Volunteering.

Diana facilitated a great discussion around why people volunteer and what the benefits of volunteering are, whilst acknowledging the challenges. It was wonderful to see the group sharing with one another and realising they have a lot in common with their motivations for volunteering and supporting each other in their shared challenges.

The other aim of the Conference was to build the leadership skills of our Support Group leaders so they can feel confident in running their groups. We invited leadership and management professional, Greg Zimbulis, to speak on ‘simple, easy to apply leadership actions to make things happen.’

Greg took our leaders through how to be a more influential and effective leader of their support group; increase participant numbers; increase community awareness and engagement and many other points. He also asked them to answer one important question: “what outcomes would you most like to see change or improve in your group?”

Greg spoke to our leaders about the why, the what, and the how of leadership.

All the leaders in attendance received copies of Diana and Greg’s presentations, so if you’d like to hear more, please ask your Support Group leader to share what they’ve learned and their key takeaways.

John Back, Communications Manager at Parkinson’s NSW, and myself also rolled out our Support Group Education Framework which built upon the previous sessions earlier in the day. This Education Framework is all about the day-to-day operations of Support Groups, the nitty gritty.

There was lots of opportunity for leaders to discuss with each other at their tables and then come together as one group at the end. They discussed their own experience with leadership so far, wrote a vision statement for their Support Group, and learned about building a leadership team, succession planning, managing leadership burnout, and Support Group administration – including communications, financial management, annual plans, event management, and risk management. So much information was shared, it was fantastic!

Again, please feel free to ask your Support Group leader for more information.

It wasn’t all work! We broke the day up with some fantastic singing (‘**Let’s Get Loud’**), led by Kempsey Support Group Leader, Garth Fatnowna on guitar in the morning and afternoon. There were also some physical and mental exercises (‘**Get Up and Move’**) led by Inner West Support Group Leader and researcher, Paulo Silva Pelicioni. Thank you to you both for bringing the joy and laughter to the day!

Our CEO, Mary Kay Walker, finished the day with an update on Parkinson’s NSW advocacy efforts and our funding submission to the NSW State Government. Mary Kay emphasised that despite our name having 'NSW' in it, we are not a government organisation, nor is Parkinson's NSW sustainably funded by government.

To back up our work on the funding submission to the state government, Mary Kay has met with more than 30 key officials and gathered over a dozen letters of supports from Members of Parliament to the Minister for Health, over the past few months, urging favourable consideration of our funding submission.

In the evening, we invited our leaders to join us for dinner – a way to say thank you for all the work you do, as well as to unwind after a long day.

The following day was our Community Symposium, where close to 250 people attended (including Support Group Leaders) to hear from Professor Carolyn Sue, Clinical Nurse Consultant Rachael Mackinnon, neurological physiotherapist Dr Melissa McConaghy, speech pathologist Colleen Kerr; Associate Professor Richard Gordon and Dr James Peters. Topics included MRI Guided Focused Ultrasound, exploring medication repurposing in identifying new treatments in Parkinson's, emerging therapies for swallowing, conversation, and facial expression; the impact of exercise on Parkinson's progression, breakthroughs in biomarkers, and being a nurse in Parkinson's research.

Feedback from those in attendance has been that the two days were "worthwhile," "uplifting," "wonderful," "interesting and informative" and a lot was gained from it.

Thank you to every Support Group leader and leadership team member who attended. I loved seeing all your faces and meeting some of you for the first time. You had to juggle travelling far distances, family commitments, work commitments and health concerns, so you could be there. Thank you.

For personalised support or more resources on these topics, contact the InfoLine on 1800 644 189. We're here to help!
For evidence-based information and advice call the Parkinson's NSW InfoLine

(02) 8051 1900

Parkinson's NSW InfoLine

Email: **pnsw@parkinsonsnsw.org.au**

Web: **www.parkinsonsnsw.org.au**